

BDFF CONNECTION

News, Support, and Community for Every Journey

The Quarterly Newsletter of the BDFF Summer 2026 Volume 52 Issue 77



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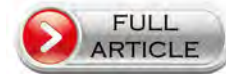
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www.bleedingdisordersfl.org

GUIDANCE ON **IRON DEFICIENCY** FOR THE BLEEDING DISORDERS COMMUNITY



Did you know that iron deficiency can affect your health even if you don't have anemia? For people living with inherited bleeding disorders, low iron levels are common and can cause symptoms such as fatigue, headaches, dizziness, difficulty concentrating, and reduced energy.

New recommendations from the National Bleeding Disorders Foundation's Medical and Scientific Advisory Council (MASAC) encourage regular iron screening, early treatment, and ongoing monitoring to help prevent complications and improve quality of life. Whether you're a patient, parent, or caregiver, these recommendations provide valuable information to help you advocate for your health. Click the button below to read the full article



Thank You, Community Foundation of Sarasota County!



We are excited to share that the Hemophilia Foundation of Greater Florida, doing business as the Bleeding Disorders Foundation of Florida, has been awarded a \$40,000 grant from the Community Foundation of Sarasota County to support von Willebrand Disease patient education and outreach programs.

Funding for this program is provided by the Evelyn Hanig Osetrwell Fund of the Community Foundation of Sarasota County.

This generous grant will help us expand educational opportunities and outreach efforts for individuals and families living with von Willebrand Disease across Florida. Through these programs, we will provide educational resources, community events, and outreach initiatives that increase awareness, promote earlier diagnosis, and connect patients with the information and support they need to better manage their bleeding disorder.

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Mission

The mission of the Bleeding Disorders Foundation of Florida is dedicated to improving the quality of life for people with related bleeding disorders and their families through education, information and referral services, advocacy and research.

Disclaimer

The material provided in BDFF Connections is for your general information only. BDFF does not give medical advice or engage in the practice of medicine. The BDFF does not recommend particular treatments for specific individuals and recommends that you consult your physician or treatment center before pursuing any course of treatment.

Executive Director's Column

Dear Friends,

Happy Summer!

I hope everyone is enjoying the Florida sunshine and making the most of this wonderful season—my absolute favorite time of year! There's something special about the long, warm days, beautiful sunsets, and the opportunity to spend time with family and friends. We've had an incredible start to the summer! Our annual Family Program at Sea World was a fantastic day filled with fun, laughter, and learning as families came together to connect with one another and strengthen their bleeding disorders knowledge. Thank you to SeaWorld for their continued generosity and partnership in making this event such a success.

We also wrapped up our 18th Annual Women & Girls Retreat, held June 26–27, 2026, in beautiful St. Augustine, Florida. Thank you **Octapharma** for your amazing support! It was an inspiring program of education, friendship, and empowerment. Engaging with the women and girls in our community and connecting, supporting one another, and creating lasting memories reminds me why this program continues to be so meaningful year after year.

The excitement doesn't stop there! We have so many wonderful programs planned throughout the rest of the summer and into the fall. From Camp Spirit and educational workshops to family events and our annual Superhero Walk, there is truly something for everyone. I encourage you to check out the calendar below and on our website www.bleedingdisordersfl.org/events/list/ and register early for the programs that interest you.

Thank you for being such an important part of the Bleeding Disorders Foundation of Florida family. Your participation, support, and enthusiasm make our community stronger every day.

Wishing you a summer filled with joy, adventure, and time spent with the people you love. I look forward to seeing many of you at our upcoming events!

Warmly,

Fran



July 14-18, 2026
July 22, 2026

Camp Spirit Summer Camp
Theater Dinner Program, Gainesville 5:30PM

July 30, 2026

Women in Bleeding Disorders Dinner
Program, Orlando – 6:30PM

July 31, 2026

Bleeding Disorders- Trivia Dinner Program,
Ocala Florida – 6:30PM

August 13-15, 2026

National Bleeding Disorders Foundation
Conference, Orlando Florida

September 26, 2026

19th Annual Superhero Walk, St. Petersburg
Florida

October 24, 2026
December 12, 2026

20th Annual Creepy Crawl, Orlando Florida
4th Annual Trailblazers Holiday Festival,
Clermont, Florida

January 30, 2027

5th Annual Latin Conference, Orlando,
Florida

We are incredibly grateful to the Community Foundation of Sarasota County and the Evelyn Hanig Osetrwell Fund for investing in our mission. Their support allows us to continue building a stronger, more informed bleeding disorders community while ensuring that individuals affected by von Willebrand Disease have access to trusted education and meaningful connections.

Thank you to everyone who supports the Bleeding Disorders Foundation of Florida. Together, we are making a lasting difference in the lives of individuals and families throughout our state.

About the Community Foundation of Sarasota County

The Community Foundation of Sarasota County is a public charity founded in 1979 by the Southwest Florida Estate Planning Council as a resource for caring individuals and the causes they support, enabling them to make a charitable impact on the community. With assets of \$605 million in more than 1,600 charitable funds, the Community Foundation awarded grants and scholarships totaling \$44.7 million last year in the areas of education, the arts, health and human services, civic engagement, animal welfare and the environment. Since its founding, the Community Foundation has been able to grant \$542 million to nonprofits in our community thanks to the generosity of charitable individuals, families and businesses. For more information, visit cfsarasota.org or call 941-955-3000.

Women's & Girls' Retreat Brings Education, Connection, and Empowerment to More Than 60 Participants

The Women's and Girls' Retreat (FAB Conference) held June 26–27, 2026, welcomed more than 60 participants for a meaningful weekend centered on education, connection, and empowerment within the bleeding disorders community. The retreat created a supportive space for women and girls to learn from leading experts, share experiences, and strengthen relationships with others who understand the unique challenges of bleeding disorders.

A Thoughtful Opening Evening of Connection and Creativity

The retreat began Friday evening with a relaxed and welcoming gathering featuring an art project, light dinner, and program overview. Participants had the opportunity to settle in, meet one another, and begin building connections in an informal and supportive environment. The creative activity set a reflective tone for the weekend, encouraging self-expression and conversation among attendees.



Saturday: A Full Day of Learning and Empowerment

Saturday's program offered a robust schedule of education led by experienced clinicians and healthcare professionals specializing in bleeding disorders and hematology.

The day began with breakfast and transitioned into the opening session, **"Women & Bleeding Disorders: From Symptoms to Diagnosis – Your Health, Your Voice — Informed Care Starts Here,"** led by **Dr. Cynthia Gauger**, pediatric hematologist and Board of Directors member of the Bleeding Disorders Foundation of Florida. Dr. Gauger guided participants through the importance of recognizing symptoms, seeking timely diagnosis, and advocating for informed, patient-centered care.



The morning continued with **"The Real Deal About Caregiving and Stress,"** presented by **Martina Willis-McCullough, BSN, RN**, Senior Medical Science Liaison in Hematology at Octapharma. This session explored the emotional and physical realities of caregiving, while offering practical strategies for managing stress and maintaining well-being.

Following a brief break and checkout period, participants reconvened for **breakout sessions with working lunch**, featuring a multidisciplinary team of experts including **Kristin Saunders, social worker at Nemours Children's Clinic in Jacksonville, Dr. Gauger, and Joanna Radcliffe, RN, also from Nemours Children's Clinic**. These sessions provided participants with smaller group discussions, personalized insights, and opportunities to ask questions and share experiences in a more intimate setting.

Community, Conversation, and Closing Reflections

The retreat concluded with program evaluations and closing remarks, as participants reflected on the knowledge gained and the connections formed throughout the weekend. Many attendees emphasized the value of hearing directly from experts while also engaging with peers who share similar lived experiences. Thank you **Octapharma** for your generous support of this important program.

A Strongly Connected and Empowered Community

During the program, participants highlighted the importance of feeling seen, supported, and informed. The combination of expert-led education and peer connection helped reinforce key themes of self-advocacy, understanding bleeding disorders, and navigating care with confidence.

The retreat underscored the power of bringing women and girls together in a dedicated space to learn, ask questions, and build community. The strong turnout and active engagement throughout the program reflect a growing need for continued education and support in this area. As the retreat concluded, one message was clear: when people are equipped with knowledge and surrounded by community, they are better prepared to advocate for their health and the health of those they care for.

Join Us for a Super Morning at the Superhero Walk!

Join us on **September 26, 2026**, at **Vinoy Park** for a fun-filled morning of food, games, and fundraising! Meet some of your favorite local heroes, including ThunderBug, Raymond, and Pete the Pelican, along with iconic characters like Stormtroopers and your favorite superheroes. Don't miss this incredible day of fun, community, and making a difference.

CLICK HERE to Register



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Twitter.com/hemophiliafl

Instagram.com/hemophiliaflorida



DONATE

It's never too early to celebrate the holidays!

Join us on December 12, 2026, for the 4th Annual Trailblazers Holiday Fest. Whether you want to walk or bike along the beautiful Clermont waterfront, enjoy festive food and family-friendly activities, or simply celebrate the holiday season with friends, there's something for everyone.

Best of all, every step, pedal, and celebration helps raise funds to support the bleeding disorders community. You might even spot a few very special holiday visitors!

However you celebrate the season, don't miss this one-of-a-kind event filled with fun, community, and holiday cheer.



[CLICK HERE to Register today](#)





For 20 years, the Bleeding Disorders Foundation of Florida has brought our community together—not just for a walk, but for a shared purpose. Every step we’ve taken has been in support of individuals and families living with bleeding disorders, ensuring they have access to education, advocacy, support, and the resources they need to live healthier, fuller lives.

Because of your generosity, your commitment, and your belief in our mission, we’ve been able to continue improving the quality of life for people affected by bleeding disorders across Florida.

Together, over the past 20 years, our Orlando Walk/Run has raised more than \$600,000 to support Bdff’s mission. Those dollars have funded critical programs, connected families with life-changing resources, and ensured that no one in our bleeding disorders community has to face their journey alone.

This year, as we celebrate our 20th Annual Orlando Creepy Crawl, we’re honoring not only the journey of this event, but the incredible community that has made it possible.

Our story began with a small group of passionate volunteers who believed that no family should face a bleeding disorder alone. On December 15, 2007, nearly 100 people gathered at St. Margaret Mary Catholic Church in Winter Park for our very first Holiday Walk. It was a simple event built on hope, compassion, and a commitment to making a difference.



As our community grew, so did our event. We moved to Lake Eola Park, where the Holiday Walk evolved into the Reindeer Clot Trot and welcomed hundreds of participants each year. In 2015, Harbor Park in Baldwin Park became our new home, and in 2016 we embraced a new tradition by transforming the event into the Orlando Creepy Crawl—a celebration of community, resilience, and the strength that comes from standing together.

Through every location, every new tradition, and every milestone, one thing has remained constant: you. Whether you've walked, volunteered, sponsored, donated, or cheered from the sidelines, you have been an essential part of this journey. Your support has provided hope to newly diagnosed families, helped children attend camp, expanded educational programs, strengthened advocacy efforts, and reminded every person living with a bleeding disorder that they are never alone.

As we celebrate 20 years and more than \$600,000 raised, we invite you to be part of the next chapter. Walk in honor of someone you love. Walk in memory of those we've lost. Walk because you believe every person deserves the opportunity to thrive.

Join us for the 20th Annual Orlando Creepy Crawl and help us continue changing lives—one step, one family, and one future at a time.

CLICK HERE to Register today

